



## PATIENT IDENTITY

## Real Time Entry Form

INITIAL HOSPITAL		CURRENT PARENT HOSPITAL		Physician	
Hospital/State	Hosp. Unit No.	Hospital/State	Hosp. Unit No.		
REGISTRY No.	SURNAME	Given Names		DATE OF BIRTH	SEX

### NEW PATIENT (DATA AT INITIAL TREATMENT)

RACIAL ORIGIN - Record from list	PRIMARY RENAL DISEASE - Record from list	BIOPSY Y/N	SE. CREATININE
Other	Other		AT ENTRY

COUNTRY OF BIRTH (If Australia or NZ - Tick box)			POSTCODE AT ENTRY
AUST	NZ	OTHER COUNTRY (Please specify)	

CO-MORBID CONDITIONS AT ENTRY					
LATE REFERRAL (<3 MTHS BEFORE FIRST TREATMENT) (Y/N)	HEIGHT (cms)	WEIGHT (kg)	CIGARETTE SMOKING	DIABETES	
			N=Never F=Former C=Current	N=No O=Type 1 Insulin dependent P=Type 2 Non Insulin requiring Q=Type 2 Insulin requiring	
CHRONIC LUNG	CORONARY ARTERY	PERIPHERAL VASC.	CEREBROVASC.	DIABETES	
				N=No S=Suspected N=No	

DATE & MODE OF FIRST TREATMENT Record from List	Code	Day	Month	Year	If Pre-emptive Transplant supply Transplanting Unit and Donor Source in "Key Events" below	ACCESS AT 1 <sup>ST</sup> HD	1=Native A-V Fistula 2=Synthetic A-V Graft 3=Tunnelled CV Catheter 4=Non Tunnel CV Catheter

## PATIENT TRANSFER

FROM	TO	Date of Transfer
Name of Hospital	Name of Hospital	

## KEY EVENTS (fill in at time of occurrence for transplants, graft failures and deaths)

TRANSPLANT (Date)	DONOR SOURCE - Record from list	Transplanting Unit
	Other <small>For Code 8 and 14 Specify other related or un-related donor</small>	
GRAFT FAILURE (Date)	CAUSE OF GRAFT FAILURE - Record from list	If Transplant performed overseas - name of country
	Other	
DEATH (Date)	CAUSE OF DEATH - Record from list	Caring Hospital At Death
	Other	

COMMENTS
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# Anzdata Registry

## Real Time Entry Form

### Codes

#### RACIAL ORIGIN

- 1 Caucasoid
  - 2 Australian Aborigine
  - 3 Chinese
  - 4 Maori
  - 5 Arab
  - 61 Cook Islander
  - 63 Samoan
  - 64 Tongan
  - 65 Torres Strait Islander
  - 69 Pacific Islander – other (specify)
  - 7 Indian
  - 8 Indonesian
  - 9 Malay
  - 10 Filipino
  - 11 Vietnamese
  - 20 Other (specify)
  - 00 Patient objects to answering question
- Mixed race coded by patient's assessment

#### PRIMARY RENAL DISEASE

**Results of ANCA (Anti Neutrophil Cytoplasmic Antibody) test in association with glomerulonephritis should be entered in box marked OTHER**

- 100 Presumed GN, type undefined histologically (no biopsy)
- 110 Focal sclerosing GN (including hyalinosis)
- 111 Primary focal sclerosing GN or focal glomerular sclerosis
- 112 Secondary focal sclerosing GN
- 121 Mesangiocapillary GN with subendothelial deposits (double contour)
- 122 Mesangiocapillary GN with intramembranous deposits (dense deposit disease)
- 130 Membranous GN
- 140 Extra and intra capillary GN (extensive crescents - clinically rapidly progressive)
- 151 Mesangial proliferative (IgA+ positive)
- 152 Mesangial proliferative (IgA- negative)
- 153 Mesangial proliferative (no I.F. studies)
- 160 Focal and segmental proliferative GN (including focal necrotising)
- 170 Advanced GN (unclassified = end stage)
- 180 GN with systemic disease (specify)
- 181 Goodpasture's syndrome with linear IgG and lung haemorrhage
- 182 Proliferative GN with linear IgG -no lung haemorrhage
- 183 SLE
- 184 Henoch-Schonlein purpura
- 185 Wegener's Granulomatosis
- 186 Microscopic Polyarteritis
- 187 Scleroderma
- 190 GN other (specify)
- 191 Familial GN (specify Alport's - yes or no)
- 200 Analgesic nephropathy
- 300 Renal vascular disease due to malignant hypertension (NO primary renal disease)
- 301 Renal vascular disease – type unspecified
- 302 Renal vascular disease – due to hypertension (nephrosclerosis) (NO primary renal disease)
- 303 Atheroembolic disease (cholesterol emboli)
- 304 Bilateral renal artery stenosis
- 400 Polycystic kidney disease
- 401 Medullary cystic disease
- 402 Infantile/juvenile polycystic kidney disease
- 500 Reflux nephropathy
- 600 Pyelonephritis
- 700 Calculi
- 701 Gout
- 801 Diabetes – Type 1 (ins. dependent) **[Juvenile onset]**
- 802 Diabetes – Type 2 (non-ins. requiring)
- 803 Diabetes – Type 2 (ins. requiring) **[Mature onset]**
- 000 Other (specify)
- 001 Uncertain diagnosis
- 002 Lead nephropathy
- 003 Cadmium toxicity
- 004 Renal tuberculosis
- 005 Amyloid disease
- 006 Haemolytic uraemic syndrome
- 007 Cortical necrosis
- 008 Interstitial nephritis
- 009 Congenital renal hypoplasia and dysplasia
- 010 Loss of single kidney (specify - **trauma, surgery**)
- 011 Megaureter
- 012 Oxalosis
- 013 Cystinosis
- 014 Balkan nephropathy
- 015 Renal cell carcinoma (GRAWITZ)
- 016 Transitional cell carcinoma of urinary tract
- 017 Paraproteinaemia (including multiple myeloma)
- 018 Light chain nephropathy (benign)
- 019 Lithium toxicity

#### PRIMARY RENAL DISEASE cont...

- 020 Post partum nephropathy
- 021 Sarcoidosis
- 031 Posterior urethral valves
- 032 Pelvi-ureteric junction obstruction
- 033 Obstructed megaureter
- 034 Neuropathic bladder
- 035 Non-obstructed dilated bladder and ureters (megacystitis – megaureter)
- 036 Spina bifida or myelomeningocele
- 037 Bladder neck obstruction (incl. prostatomegaly)
- 039 Other lower urinary tract abnormalities (with secondary reflux) **(specify)**
- 040 Ureteric obstructive nephropathy
- 041 Obstructive nephropathy

#### CAUSE OF DEATH

##### CARDIAC

- 10 Myocardial ischaemia (presumed)
- 11 Myocardial ischaemia and infarction
- 12 Pulmonary oedema
- 13 Hyperkalaemia
- 14 Haemorrhagic pericarditis
- 15 Hypertensive cardiac failure
- 16 Cardiac arrest – cause uncertain
- 17 Other causes of cardiac failure **(specify)**

##### VASCULAR

- 21 Pulmonary embolus
- 22 Cerebrovascular accident
- 23 Gastrointestinal haemorrhage
- 24 Haemorrhage from dialysis access site
- 25 Haemorrhage from transplant artery
- 26 Aortic aneurysm – rupture
- 27 Haemorrhage from elsewhere (specify)
- 28 Bowel infarction

##### INFECTION

Please enter code for nature of infective organism, after the code for site of infection

Please **specify type of organism**

eg Staph, CMV, Candida, etc

**eg 321 Lung infection – bacterial (staph)**  
**322 Lung infection – viral (CMV)**

- |                                                                  |             |
|------------------------------------------------------------------|-------------|
| 31 CNS                                                           | 1 Bacterial |
| 32 Lung                                                          | 2 Viral     |
| 33 Urinary tract                                                 | 3 Fungal    |
| 34 Wound                                                         | 4 Protozoa  |
| 35 Shunt                                                         | 5 Other     |
| 36 Peritoneum                                                    |             |
| 37 Septicaemia – site unknown (specify organism)                 |             |
| 38 Liver (incl viral hepatitis) (specify A, B, CMV, herpes, etc) |             |
| 39 Other site (specify)                                          |             |

##### SOCIAL

- 40 Withdrawal for psycho-social reasons
- 42 Suicide
- 44 Accidental death (specify)
- 45 Withdrawal for cardiovascular comorbid conditions
- 46 Withdrawal for cerebrovascular comorbid conditions
- 47 Withdrawal for peripheral vascular comorbid conditions
- 48 Withdrawal related to malignancy
- 49 Withdrawal related to dialysis access difficulties (AVF, Tenckhoff, etc)

##### MISCELLANEOUS

- 50 Hepatic failure
- 51 Uraemia caused by graft failure
- 52 Pancreatitis
- 53 Bone marrow depression
- 54 Cachexia
- 56 Malignant disease
- 57 Perforation of abdominal viscus – peptic ulcer, diverticulum, appendix
- 58 Dialysis dementia (aluminium)
- 59 Other **(specify)**
- 60 Immunodeficiency due to viral infection **(specify organisms involved)**
- 61 Chronic respiratory failure
- 62 Sclerosing peritonitis

#### MODE OF FIRST TREATMENT

- A Hospital or Outpatient APD
- L Hospital or Outpatient CAPD
- B Hospital HD
- D Satellite HD
- G Transplant in Aust/NZ

#### SOURCE OF DONOR KIDNEY

- 1 Deceased Donor (DD)
- 2 Sister (if twin, record 6 or 7)
- 3 Brother (if twin, record 6 or 7)
- 4 Mother
- 5 Father
- 6 Monozygotic (identical) twin
- 7 Dizygotic (non-identical) twin
- 8 Other related living donor - SPECIFY
- 9 Son
- 10 Daughter
- 11 Husband
- 12 Wife
- 13 Cousin
- 14 Unrelated living donor - SPECIFY

#### CAUSE OF GRAFT FAILURE

##### REJECTION

- 10 Hyperacute rejection (within 48 hours of transplantation)
- 20 Acute rejection at anytime, causing graft failure
- 40 Chronic allograft nephropathy (slow progressive loss of renal function, not due to recurrent original disease or acute rejection)

##### VASCULAR

- 50 Renal artery stenosis
- 51 Renal artery thrombosis
- 52 Renal vein thrombosis
- 53 Renal vessel haemorrhage (primary)
- 54 Renal vessel haemorrhage (secondary)
- 55 Embolus – thrombo
- 56 Embolus – cholesterol
- 57 Haemolytic uraemic syndrome

##### TECHNICAL

- 60 Non-viable kidney (due to pre-transplant cortical necrosis)
- 61 Cortical necrosis Post transplant (not due to rejection)

- 70 Ureteric and bladder problems

##### GLOMERULONEPHRITIS

- 82 Mesangiocapillary GN with subendothelial deposits
- 83 Mesangiocapillary GN with intramembranous deposits (dense deposit disease)
- 84 Focal sclerosing GN (including hyalinosis)
- 85 Membranous GN
- 86 Mesangial proliferative GN (IgA positive)
- 87 Goodpasture's syndrome
- 88 Intra and extra capillary GN with extensive crescents (clinically rapidly progressive)
- 89 Other (specify)

##### DRUG THERAPY

- 90 Complications of drug therapy requiring reduction or withdrawal of steroid and/or immunosuppressants
- 91 Non-compliance with therapy – causing graft failure
- 92 Rejection following I/S reduction due to malignancy
- 93 Rejection following I/S reduction due to infection

##### MISCELLANEOUS

- 00 Other (specify)
- 01 Donor malignancy
- 02 Malignancy invading graft
- 05 BK virus nephropathy



## PATIENT IDENTITY

## Real Time Entry Form

INITIAL HOSPITAL		CURRENT PARENT HOSPITAL		Physician
Hospital/State	Hosp. Unit No.	Hospital/State	Hosp. Unit No.	

  

REGISTRY No.	SURNAME	Given Names	DATE OF BIRTH	SEX

## COURSE OF TREATMENTS

**Please report any changes of treatments, and reasons for dialysis modality change**

Treatment Code (Use Codes Below)	Date	Reason for Change (Use Codes Below)	Other (Reason)

- A APD / IPD Hospital
- C APD / IPD Satellite
- E APD / IPD Home
- L CAPD Hosp/Outpatient
- M CAPD Home
  
- B HD Hospital
- D HD Satellite
- F HD Home
- G Transplant in AUST/NZ
- H Date of last post graft dialysis
  
- X Transplant Overseas
- I Graft function Temporary/  
Permanently ceased  
(Date return to dialysis)
- J Own kidney function  
recovered. Dialysis ceased
- K Date of last visit  
if lost to follow up

### REASON FOR MODALITY CHANGE

- From CAPD to APD
- From APD to CAPD
- From any form of PD to HD
- From HD to any form of PD
- 10 Recurrent / persistent peritonitis
- 11 Acute peritonitis
- 15 Tunnel / exit site infection
- 16 Diverticulitis
- 20 Inadequate solute clearance
- 21 Inadequate fluid ultrafiltration
- 22 Excessive fluid ultrafiltration
- 27 Abdominal abscess
- 30 Dialysate leak
- 31 Catheter block
- 32 Haemoperitoneum
- 33 Catheter fell out
- 35 Hernia
- 36 Abdominal pain
- 40 Abdominal surgery
- 41 Sclerosing peritonitis
- 42 Peritoneal infection
- 43 Multiple adhesions
- 44 Pregnancy
- 45 Haematuria
- 46 Pleural effusion
- 47 Cardiovascular instability
- 48 Geography – poor access to dialysis services
- 49 Vascular access problems
- 50 Patient preference
- 51 Unable to manage self-care
- 60 Recovery of renal function
- 70 Transplantation
- 80 Death
- 81 Transfer outside Australia or New Zealand
- 82 Other surgery
- 83 Hydrothorax
- 85 Poor nutrition
- 86 Scrotal oedema
- 90 Planned transfer after acute PD start
- 91 Planned transfer after acute HD start
- 99 Other (**specify**)